

**NDSD Transition Team
Public Comment/Input**

1/21/10 Email

Thank you so much for the hard work you are putting into this endeavor. The mother of a deaf child I appreciate each one of you.

My 15 month-old daughter was diagnosed as profoundly deaf at birth. She had hearing aids put on at 4 months old. She just had a cochlear implant put in and was activated this month. She has a wonderful TOD through PIP Outreach.

Our main concern for our daughter right now would be for next fall as she is growing in her need for some outside interaction/learning/socialization, there is nowhere for her to go. We live 100 miles from the School for the Deaf, so putting her into their daycare is not an option. I would like to see an unbiased outreach Day School (for Preschoolers). I also would be willing to help with this.

Please bring up in your discussion what avenues there are for children like her. If diagnosing these children at birth in North Dakota, shouldn't we be able to offer a solid foundation of learning and social interaction for them as well.

I have just started the application process for a Hands and Voices Chapter here in ND. Please let me know if you are interested in helping in any way!
www.handsandvoices.org

Good luck in your meeting.

12/15/09 Email

I read with great interest the minutes/notes from your October and November meetings. Visioning with others interested in serving deaf and hard of hearing persons from around North Dakota is an exciting proposition. Having been involved with the field of deafness for almost 30 years, both personally and professionally, it is invigorating to consider new and expanded ways to serve people who are deaf or hard of hearing and their families. I have an adult son who is Deaf and coordinate services for deaf/hard of hearing students at the University of North Dakota.

A couple of areas that come immediately to mind are technology and family support. A statement in the November report reports that "Research from Gallaudet University shows that the most influential factor regarding positive outcomes for deaf and hard of hearing students is the quality of instruction." Other research suggests that a healthy parent-child bond and strong attachment are essential for optimal language development in deaf children (Pipp-Seigel & Biringen, 1998) which will ultimately lead to successful educational (and personal) outcomes.

The task force is at the beginning of its mission to re-vision what NDSD will mean to ND residents with hearing loss - I can imagine a central resource to provide statewide interpreter services, media captioning services, training for employers (who employ deaf persons), statewide assessment team to assess deaf/hard of hearing children in their home schools - there are so many needs that with innovative solutions will improve the quality of education and life for ND residents

with hearing loss. Senior Citizens with hearing loss is another group I see your task force addressing - again, so much potential for positively impacting people's lives through education, technology and family support.

I will be watching the progress of the Future Services Plan Transition Team with great interest!

12/13/09 Email

I love your comment about ND being a "...leader rather than just followers". My son is now a year old and has a moderate hearing loss. This is all new to me but I cannot imagine where my family would be without the outreach service provided to my son and his family. I got a phone call from an audiologist saying he had a hearing loss and that before he is six months he will need to have hearing aids. Thankfully we were connected with the outreach program and they were there to offer support and answer questions. Everything about our outreach support has been great however I feel my son would benefit more with additional time with her weekly. Our goal for our son is that he will be able to enter public school like his older siblings and get a great education. However if he is not able to learn in this manner I want the option of him going to another school

12/12/09 Email

As a parent of now a young adult with a hearing impairment there are a few things I would like to express.

When he was younger the school's (local) first reaction was to send him at 3 to the School of the Deaf. Just receiving a fairly new diagnosis this was I think one of the most traumatic discussions that we had as a family. Especially when the lead administrator of the school we attended, pounded his fist on the desk and asked "what do you want from us".

Luckily we had great support from outreach staff from the School of the Deaf who came to our home frequently, combined with great staff in special ed, he stayed in the local school district, which I think is a real success story of inclusion.

As a parent I have to say it has been a difficult decision to be stuck in the middle of the hearing world and deaf world. We took a lot of insults from those who were in the deaf world and accused of us some neglect as the decision we made was not to send him to the school. That decision was not made easily or lightly. (Those insults did not come from individuals at the school) More so, from adults with hearing impairment and deafness at conferences, etc. So I think more work could be done with families to better prepare them for what may lie ahead. I feel all families should be connected to family organizations for emotional support.

The School of Deaf over the years provided great consulting services. We contacted the school frequently and were met with warm and caring responses, which in light of the above situation was a breath of fresh air. We could speak openly and frankly with people who understood. From behavior management to equipment

consultation, recommendations etc, consultation was great. I would like those to increase.

He does not have a profound hearing loss, but it is quite severe and had 2 words of speech when he entered the education world...

His success, in part, I believe firmly was due to his own will and drive, dedication from special ed services and the great consultation from the School of the Deaf and the family determination on many issues in partnership with the Local education program. We also have a wonderful audiologist who provided in service training with school of deaf staff, made recommendations for accommodations in the school setting and monitoring, and attended IEP meetings. When we were seeing behavior patterns we consulted with school psychology staff for recommendations, as we were seeing OCD type behaviors that the local school had missed.

This is not to say that there is not room for the School of the Deaf, and that there should not be a campus. Families HAVE to make decisions based on what they feel is the most appropriate for their child and family. If we had not seen improvements at the local school with all of the support he received and had not persevered in that area, the campus would have been crucial for us. But he excelled. Could he have excelled more on campus. We do not know. Perhaps. I do know that socially, psychologically and behaviorally for him this would not have been a good situation, and financially, we may not have been able to make it work.

There are some things I wish we would have had in the local school setting:

1-while we received great consultation services. I think again, this should be increased. Utilize staff to go to local settings. Somehow we have gotten further and further away from that, and this is what kept him included in the local setting. It is much easier in my opinion for staff to go to outreach areas than it is for families to go to the school. While I understand it...I also understand the financial constraints and time constraints this can add to a family. Expense, time away from work to make the trip, added to the expense of therapies, trips to the therapist, audiologist, aides and adaptive equipment, depending on the family situation this can place undo financial and emotional burden on families.

2- with the wave for implants, consultation will be vital and should be adapted as such. He does not have an implant, as in doing so we were told years ago that while he was a candidate he would not have been able to play sports. So when the discussion came up, we posed the question to him at age 11 of what he wanted to do. After all, he understood fully, this was his life, and how do u take away something that was the best motivator of all for him. Sports. We could not do that to him. His decision was not to have the implants as in his words said "I have all my life to get implants, I do not have all my life to play sports". We were then insulted by hearing parents for that decision as "after all you are the parent, what you say goes" Not that easy. And in some ways, not our right to make a moral decision when he was capable and able.

3-at the time Minot State was the only facility that had a closed caption program that would have helped him immensely in real time captioning through use of a computer. We could not obtain that as the school said it was too costly.

How unfortunate as we know how important closed captioning has been in his life. Accommodations such as preferential seating etc., having a teacher of the hearing

impaired can only go so far. I think for families who have their child included in the regular education setting, this is a crucial accommodation and should be utilized for all children who need it. This would have assured that with auditory trainer, the closed captioning would have made the difference in whether he was fully understanding what was being taught as an additional accommodation. Why could this not be done through the school of the deaf? Perhaps it is and I am unaware of it.

4-Why can't we add ASL as an additional language for credit in the schools. There was no way he would have survived a Spanish or other language class. English for hoh/deaf students is difficult let alone a foreign language class. I have always thought that if ASL was offered would also open up another world for hoh/deaf students. This is acceptable in many other states as offered as a foreign language credit.

We were also told that if he was to be accepted in a 4 year college that a foreign language was going to be needed. How do we get hoh/deaf students into a 4-year program or beyond if this is an issue. Luckily the college he is at currently, did not need the foreign language. But there are schools that do enforce this. Why would we allow a student to make a decision of what post secondary he will attend based on this fact. It is silly to stifle our students in this way and I think this should be changed. ASL could be taught over IVN, would engage regular ed students, provide communication with peers. I feel it just makes good sense. What will it take to make this change? Why can ASL not be taught in schools as a foreign language credit? In this sense, he did not have the same advantage as other hoh/deaf students who attend the school as certainly he would have been taught ASL, and we would have been taught ASL. This was not taught to him but also what a difference this would have made in his life. While we asked for this in the IEP, and he had a teacher for the hearing impaired. This did not happen. It did not happen for various reasons. 1-teaching staff was to stretched, as they were pulled to help other students on an IEP (non hearing impaired students), 2-this would have been in addition to what was already being done. However, if it had been a class with credit. It would have been included as part of his day. ASL was only being taught through classes in parts of the state which were many miles away. What a huge disadvantage for he as a student and us as a family. Why not offer to all students. What better way for regular ed students to learn to communicate with deaf/hoh individuals. To many times deaf/hoh individuals are isolated due to communication! Would this not help to bridge this gap?

5-I also think a better job needs to happen with VR staff and the partnership with School of the Deaf, special ed and regular ed. Senior year is too late, in the IEP process. I also think that the goals of these students are often not challenged enough and some staff need to set higher standards of what these youth and young adults can accomplish. We were highly encouraged to send him to a trade school or Job Corp when he had much more potential and is not what he wanted to do. With graduation credits, senior year is much, much too late. How deflating when that was the recommendation and his dreams were being ignored. We fought that and he is doing well in a 4-year post secondary program.

6-family support is crucial and the best family support can come from other families. Family support needs to be as diverse as the families and in a variety of ways. We found other families on our own. However, the first family we met was when he was nearly 5 years old. How we desperately needed to speak to other families from Day 1. The isolation, fears, emotions could have been minimized had this been done. Professionals have a place and are also a wonderful support system..however..is not the end all be all. Family support is crucial. As is mentor support for students.

7-another thing regretfully that he did not take advantage of is programs offered at the school. Camps etc. I think in part due to the fear that if he went to a camp, that certainly he would get sent to school there. We tried everything to get him to go! This was a huge fear for him and leaving home. I do not know where this fear came from. I know in part some was due to what he had heard initially from administrative staff "that that is where he belonged"., but if there were other conversations that took place that he overheard/misunderstood/ we may never know. Nonetheless, this was his fear. and social adaptation, etc. could have been much better had there been more interaction with the school as he grew older. As he grew older consultation became less and less. If it had continued on a regular basis, people would have been familiar, and he may have been more inclined to attend some of the great things on campus. Social isolation has been an issue for him. Some is his own choosing but in other ways, if some of the above had been done, I feel he would have excelled even further than he has. For this we feel very fortunate at how well he has adapted to any new surroundings. While socially he can be a social butterfly, in many areas he becomes introverted and does not participate. He is self conscious of his speech, becomes very critical of himself, almost to the extreme, showing still some OCD tendencies. This has taken much work on all of our parts, to also be super sensitive on how things for him will be interpreted.

Again, the school plays many rolls. I don't think that the campus should be closed but I do think that we are seeing new and great things as far as inclusion which should be embraced. Who better to provide outreach services, consultation, for students to be included than the school itself. But I also think this needs to be done throughout the students high school career as well.

Thank you

11/07/09 - Email

Good evening,

I would like the team to address the need for an Oral/Deaf Education program in the state. With the increase in Cochlear Implants in younger and younger children, I would like to think we would dedicate resources to this type of specific program something similar to those in Missouri, Minnesota and Nebraska. Please add this as a point of discussion. As the parent of a three year old, we are needing to look outside the state to find a dedicated Oral/Deaf Education program.